

EUROPEAN DOWN SYNDROME ASSOCIATION

June 2024

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REMINDER EDSA WEBINAR



Dear EDSA members,

Wednesday 19 June, 17.00 hr CET EDSA organises a webinar about the

Early Intervention "Small Steps". Programme

The speakers will explain and show why and how Small Steps is used in their country, and introduce the Web Application.

Did you register? Here is the registration link:

https://us06web.zoom.us/webinar/register/WN_jJexbNniSxe_TkMqWNbxng#/registration

Did you forward this information to your members?

It is a very interesting topic for families with very young children!

The webinar will be in English.

Translations are available in Czech, Turkish, French, German, Ukrainian, Croatian.

More information: https://www.edsa.eu/small-steps-an-early-intervention-program/

Best regards

Cora



EDSA MEMBER OF THE MONTH

AVVENTUNO (Switzerland)



<u>AVVENIRE – Future</u>

AVVENTURA- Adventure

21 (VENTUNO) - Trisomy 21

AVVENTUNO was founded in Canton Ticino (southern Switzerland) in 2015 by Monica & David Induni. Before this date no association for people with Down Syndrome existed in the Italian-Speaking Canton of Switzerland.

Over the last 9 years built a solid credibility based on the commitment and quality of its staff and its dedication. We are always available for any information regarding a recent diagnosis of Trisomy 21 and we are known as a point of reference for both families and professionals (therapists, teachers, educators), as well as for local organizations, in a careful balance between proximity and widespread collaboration together with its very own specialized profile of scientific in-depth analysis. We work with hospitals and gynecologists that put us in contact with new families as soon as a diagnosis arrives, and newly arrived families in Ticino (e.g. from Ukraine and Italy) with a child with Down Syndrome are encouraged from local services to contact Avventuno for advice and assistance.

Since 2023, a member of the Association's Steering committee has Down Syndrome and she is a very valid and competent addition to our committee's work.

We follow approximately 60 individuals with Trisomy 21 and their families, mostly from Ticino (plus some families in Northern Italy). We provide direct parental support and guidance, educational accompaniment, advice and courses for professionals, feedback on DS conferences and congresses, continuing education to teachers and educators.

We believe one of our strengths is our professionality: since 2020 we have employed professionals in various areas to provide highly qualified work that opens doors to inclusion in schools and in the work environment, as well as autonomy projects for teenagers (DADO group) and summer-camp inclusions. We also organize numerous training courses are for parents and professionals (i.e. "The learning profile in T21", "Signing / bimodal communication" / "Executive functions in intellectual disability", etc.) and work with the local university, giving courses to teachers and future teachers.

Avventuno is in close contact with other DS associations in Switzerland (ART21 and Insieme21) in Italy, as well as in the international network of EDSA, DSI and T21RS.

Avventuno have been collaborating since 2022 in the H&M "My Store" project in the centre of Lugano. The project involved a professional photoshoot, posters of young models with DS on display and Avventuno gadgets permanently present at the shop for purchase. This has raised awareness locally on the issues of inclusion and personal



fulfilment for people with Down syndrome. In-store events are arranged for special occasions and internships have been arranged for some of our young people with Down Syndrome giving them invaluable work experience in the shop. Avventuno is also arranging other collaborative internships locally in some hotels and restaurants.

'Daniel' is a book (in Italian) published by Avventuno. The story explains Down Syndrome to school children and work is in progress translating it into English and in Spanish. Avventuno is also the author of a booklet 'Birth of a Baby with Trisomy 21' - at first it was only in Italian but in collaboration with ART21 and Insieme21 in the French and German speaking parts of Switzerland it is now a four-language version (German, French, Italian, English) — the booklet has been widely distributed in Switzerland to clinics, hospitals, paediatricians.

For any further information please contact Monica Induni on monica.induni@avventuno.org.







EUROPEAN ELECTIONS



Use your vote (If you have one). Right to vote of people with intellectual disabilities and European elections 2024

There are still voting restrictions in several EU countries, especially for persons with intellectual disabilities.

Inclusion Europe published <u>a video</u> about voting rights for people with intellectual disabilities under guardianship in Europe.

The <u>UN Convention</u> on the Rights of Persons with Disabilities reaffirms the right to vote and to be elected for people with disabilities. However, there are still restrictions in the European Union for people with intellectual disabilities.

Whether a person with intellectual disabilities can or cannot vote is in many countries restricted based on their legal capacity and placement under guardianship. This is a violation of their rights.

In 2019, there were around 800.000 people from 16 Member countries that did not have the right to vote nor to stand for election based on their disability.

Based on the <u>Inclusion Europe reaserch</u> in 2023, among the 27 EU countries:

- 15 countries grant full voting rights for people with intellectual disabilities under guardianship:Ireland, Germany, Sweden, the Netherlands, Italy, Finland, France, Austria, Latvia, Spain, Slovakia, Slovenia, Croatia, Luxembourg, Greece.
- 8 countries grant limited voting rights for people with intellectual disabilities under guardianship: Belgium, Hungary, Malta, Portugal, Lithuania, Czechia, Romania, Denmark.
- 4 countries grant no voting rights for people with intellectual disabilities under guardianship: Estonia, Bulgaria, Cyprus, Poland.



The European Parliament voted <u>a resolution</u> in 2023 saying that people with disabilities, regardless of their legal capacity restrictions, should be allowed the right to vote. The EU strategy also mentions the need to improve the accessibility of the right to vote of people with disabilities and to be elected.

"There are more than 7 million people with intellectual disabilities and their families in the European Union. Our votes matter. Election campaigns must also target people with intellectual disabilities and their families. To reach us the political groups must talk and listen to us. Both elections and campaigns must be fully accessible." — Jyrki Pinomaa, President of Inclusion Europe

The voting and accessability issue:

Voting rights for people with intellectual disabilities

Easy to read materials:

People with intellectual disabilities and access to elections

Easy-to-read materials about Euroepan elections.

Easy to read magazine about the voting issue

Source: Inclusion Europe



NEWS FROM EROPEAN DISABILITY FORUM



EU MUST SUPPORT RIGHTS OF WORKERS WITH DISABILITIES WITH DISABILITY **EMPLOYMENT GUARANTEE**



On the occasion of International Workers' Day and ahead of the European election, the European Disability Forum calls on the next mandate to establish a "European Disability Employment and Skills Guarantee" that promotes quality employment of persons with disabilities.

Our 2023 report on the Right to work shows that persons with disabilities are much more likely to be unemployed or underemployed in the European Union. Only 51.3% of persons with disabilities are employed, compared to 75.6% of persons without disabilities.

The next mandate must significantly improve these disappointing numbers through the establishment of this "European Disability Employment and Skills Guarantee". This guarantee must be supported by an earmarked budget from the European Social Fund to ensure employment in the open labour market. It must be modelled after the successful Youth Guarantee and:

- It should be open to people receiving disability allowance and allow them to retain this allowance when in work, training, or education.
- It should not have any age restriction.



- A strand should be allocated to assist in providing reasonable.
- Accommodations for the person at work through both technical and financial support.
- The Guarantee should emphasise employment in the open labour market. It should exclude sheltered workshops exclusively for persons with disabilities, where workers do not have the legal status of employees and are not paid in line with minimum wage requirements.

Yannis Vardakastanis, President of the European Disability Forum, said:

Persons with disabilities have the right to work, but more, it's our right to have support, accommodation, and an accessible environment – and this is not our reality in the Union. The Union needs to commit to guaranteeing the dignified, quality employment that so many have fought for during the years.

Andre Felix, 01 May 2024, European Disability Forum website



NEWS FROM THE PROJECTS WITH EDSA MEMBERS IN THE CONSORTIUM





Giorgia Scivola, from AIPD, collects certificate for Valueable

The Valueable Network was highly commended at the Disability Smart Award 2024 for their work to improve the lives of disabled people. The Valueable Network was highly commended in the Disability Smart Global Disability Inclusion category at an awards ceremony in London on 30 April, hosted by Business Disability Forum and held in partnership with Bloomberg.

The Disability Smart Global Disability Inclusion Award recognises organisations that have made a tangible, positive impact to the lives of disabled employees, customers, or service users across a global setting. This might be through the introduction of best practice solutions, a new campaign, service or product, where the benefit has been achieved across a number of different geographic regions.

The judging panel awarded The Valueable Network highly commended status for their work providing vocational training and job inclusion to people with learning disabilities in the hospitality sector throughout Europe.

In their feedback, the judging panel said:

"Leveraging support tools and stakeholder partnerships, The Valueable Network has helped to create work environments where people with learning disabilities can take part in meaningful work and gain valuable experience, either as interns or employees. Their ethos, to reduce the disability employment gap that persists in Europe, is one that we can all support.

"We particularly noted how the project has proved scalable, supporting individuals across 8 countries. It is this innovation of scale we want to recognise by awarding The Valueable Network highly commended status."

Now in their tenth year, Business Disability Forum's annual Disability Smart Awards recognise organisations and individuals that are improving the life experiences of disabled employees and consumers by removing barriers to inclusion. The awards are a platform for sharing evidence and learnings from real life projects that have had a positive and tangible impact on disabled peoples' lives. Awards were given across 10 categories this year.



The Accessibility Discovery Centre at Google won in the Global Disability Inclusion category this year and HSBC was a finalist. We are honoured to have been in this competition alongside such big names!

Diane Lightfoot, CEO of Business Disability Forum, said: "I would like to congratulate all of the organisations who were recognised in the Disability Smart Awards this year. Their efforts and achievements are already significantly improving the life experiences of many disabled people, but I also hope their stories will provide real-life examples of 'what works' for all businesses to follow."

Find out more about Disability Smart Awards 2024 on <u>Business Disability Forum's Disability Smart Awards 2024 page</u>.



MAKE THIS NEWSLETTER REALLY YOURS!

Have you got any news that we could publish in EDSA newsletter? Please send us any information you would like to announce and we shall be happy to disseminate it all over Europe!

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